

Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

Research Subgroup

December 5, 2012; 9-10 am

CORO West, Suite 304 A

Present: Donna Cimini (RIMMRI), Ana Tua Fulton (Butler), Brian Ott (RIH), Ed Stopa (RIH), Gehad Subaiea (URI), Leslie Fontana (RISD), Peter Snyder (Lifespan, RIH), Stephen Salloway (Butler), Lindsay McAllister (Lt. Governor Roberts).

1. Review of Edits and Suggestions Regarding the National Plan and Vermont State Plan

- a. The participants worked through all of the edits, comments and suggestions that had been submitted as changes to the how the NAPA and VT plans approached this work.
- b. A draft reflecting this work will be attached.

2. Inter-Institutional Cooperation to Develop a Patient Registry

- a. Brian Ott started a registry for adults with complaints, memory problems, etc. – the idea is to get them early with a minimum data set (need to define).
- b. At Butler and RIH alone, there are 20-30 clinical trials. We need a unifying medium to share information.
- c. Ideally, the registry would want be able to enroll people from providers and researchers across all institutions in RI and enable data sharing across institutions as well.
- d. The best example of collaboration in the state so far is the RI consortium for Autism Research. The legal/rule-based model here is something they've already worked on – we need to look into this and bring this topic back to the subgroup in the future. URI is involved with RICAR and may be a good starting place for inquiry.
- e. The State can play a role in bringing URI, Brown, etc. together in their gerontology-centered work.
- f. AZ has a statewide registry that spans institutions; may serve as a good example for us to look into.
- g. We must also consider the role of the Trial Match program at the Alzheimer's Association. This program provides information on: Who? How do you contact the team? And basic inclusion/exclusion information.
 - i. The subgroup will receive a link to the trial match program in the coming weeks. Lindsay will send it out and seek feedback on what is there and working and what might be missing/what needs are not being met.

3. Design Goals for a State-Based Research & Resources Website

- a. There are major questions about the creation of this resource: Who is going to manage this website? Who is our web host? Where do the FTE's (staff) come from and how are they paid? What kind of workload burden would this project be? Would it be best to seek funding to expand the

Alzheimer's Association website rather than reinvent the wheel? Would that website be capable of serving the role we are envisioning?

- b. How can we use what we know from the ADRC and The POINT to inform this new resource?
 - c. What is going on at the URI Geriatric Education Center that would impact or be impacted upon by the creation of this website?
4. The meeting was adjourned. The next meeting will be January 10th at 4 pm in CORO West, Suite 304 A.
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